

**DEVELOPMENTAL ARTICLES**

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**WHO IS IN ... AND FOR WHAT? AN ANALYSIS OF  
STAKEHOLDERS' INFLUENCES IN CBR**

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**ABSTRACT**

*CBR builds on the active involvement of people with disabilities, volunteers, community rehabilitation workers, trainers, planners, and policy makers and can therefore best be viewed as a 'web of interactions' between and among these people. To explore the roles of the people involved in the processes of CBR, a stakeholder analysis is being used. In this analysis different stakeholders in CBR have been identified and their position and influence in the process has been anticipated. This type of analysis sheds light on the processes of CBR and, consequently, makes them accessible for research. It also allows developing strategies to get the most effective support from the stakeholders involved. The relevance and efficacy of the different stakeholders will, to a large extent, be defined by the requests and expectations of the other stakeholders involved. In order to assess the stakeholders, a normative framework which includes not only the position and competency of the different stakeholders, but also their decision-making capacities and information needs, was constructed.*

**INTRODUCTION**

Nickols (1) used the term 'nexus of contracts' to describe the relations between and among the various stakeholders. Although in CBR, stakeholders will most likely not label their relationships as based on 'contracts', and these are probably better described as based on 'expectations' - the term covers the process of CBR nicely. Nickols further elaborated that "the success of an organisation is a function of the extent to which the needs and requirements of its stakeholders can be integrated and balanced, without sacrificing any one to the other". The interdependency of stakeholders, including key elements such as mutual influence and accountability, is crucial in working with this concept.

A basic stakeholders analysis will take three steps (2):

1. Identify stakeholders:

This includes listing the different stakeholders and a description of what they actually do.

2. Anticipate the kind of influence they have:

Most importantly, here is how much power each stakeholder has in the organisation, what the needs and expectations are of the stakeholders, and how these can be satisfied by the stakeholder themselves or by other stakeholders involved.

3. Develop strategies in order to get the most effective support.

This strategy should match the competencies and positions of various stakeholders to influence the organisation. It includes training, supervision, information, etc.

What stakeholders actually do (step 1 of the analysis) can be described as a series of actions or interventions, for example, demonstrating exercises to family members, discussing the impact of having a disability with community leaders, instructing village community workers, or educating trainers. The effects of all interventions made by the different stakeholders are believed to reflect an improvement in abilities or a change in the position of the person with a disability. However, the interventions themselves, the involvement and compliance of the stakeholders, and the effects on the different stakeholders are seldom analysed. For example, it is not clear if and how increased knowledge about disabilities changes the stakeholders' attitude towards people with disabilities, or makes her more competent to fulfil her role in the rehabilitation process. Nor is it self-evident whether or not an increased ability of a person with a disability is due to increased knowledge, or competence of family, or community members.

A study done by O'Toole in Guyana showed that the reactions of mothers to a parental involvement programme were very different and often depended on the various responsibilities the mothers have (3). He concluded that, "Future research could usefully investigate the variables within the child, family and community which may contribute to the effectiveness of the programmes".

Hereafter, a short discussion on the different stakeholders as found in the relevant literature is presented.

## **STAKEHOLDERS IN THE COMMUNITY**

The most prominent stakeholders in the community are the person with a disability, the family / family trainer, and the Local Supervisor. However, they are not the only ones. More stakeholders can be identified in the political and administrative system (e.g. administrators, council members, civil servants), in the informal health system (e.g. traditional healers, traditional birth attendants), educational services (e.g. teachers), and in the local business community (e.g. shopkeepers, craftsmen, credit scheme holders). In general, they will be 'latent' stakeholders, meaning that they become involved when a specific issue is raised.

In CBR literature, traditional healers are often included in the CBR process, as it is believed that many of the people with disabilities who get involved in CBR are also looking for help in the traditional care system. In addition, the general public or 'the community', is addressed with regards to (perceived negative) attitudes towards people with disabilities. Attitudes towards people with disabilities have been studied in different ways. Speakman (4) used an "Attitudes Towards Disabled People" questionnaire, but no further studies are known using this, or a similar, instrument. Jackson (5) examined the levels of knowledge and experience that trainee social workers have about disability, as well as their beliefs and attitudes towards disability and rehabilitation. She found that these trainee social workers generally held positive attitudes towards people with disabilities and nearly all students expressed a belief in supernatural causes in conjunction with natural causes. Anthropologists and sociologists have also done descriptive studies. In a study of the Songye people in Zaire/Congo, Devlieger (6) noted that there is not a general negative attitude towards people with disabilities and that deviations in the body can induce a higher, lower, or indifferent status. People with an indifferent status ("faulty people") encounter an attitude of indifference towards their own situation. Instead, attention is directed at the problem underlying the fault. The person with a disability is not seen as abnormal but liminal, and she is seen as a person, like any other, with a right to development. Jackson and Mupedziswa (7) carried out a study on beliefs and attitudes among people with disabilities in rural Zimbabwe. They concluded that the people with disabilities included in their study, do not hold a consistent worldview, and that they use rehabilitation services "... either in conjunction with traditional services or to their exclusion regardless of beliefs of casualties". In their opinion 'negative' beliefs of causality did not exclude people with disabilities from community life.

Kisanji (8) studied Tanzanian proverbs and presented examples in which people are urged to contribute to the welfare of the community according to their ability. He pointed out that in the history of Western countries, as in that of developing countries, examples of hiding, excluding, abandoning, and killing people with disabilities can be found. He concluded that “Historically, therefore, attitudes towards disabled people have been a mixture of persecution as well as tolerance. However, the tolerance shown has been paternalistic”. Research on the roles of people with disabilities in the community, and the community’s attitudes, has been descriptive and is fragmented. Studies about a change in attitudes are rare and lack a proper research design (specifically a description before and after the intervention programme). An exception is a recent research study carried out by Thorburn (9). She used a proper research design in a study of the attitudes towards childhood disabilities in Jamaica. The data “provided a baseline for change in knowledge, attitudes and practice in community based service for children with disabilities”. No follow-up research on these base-data is available at the moment.

Whereas, studies describing and influencing attitudes in the ‘general public’ are reasonably common, studies influencing specific groups within the community are rare. An exception is probably the study on involving local craftsmen in the training of people with disabilities (10). The total absence of studies about influencing ‘policymakers’ in the community and at other levels is noteworthy, as many project planners include influencing policymakers as a dominant aim of their projects.

### **Person with a disability**

The first stakeholder to be discussed is the person with a disability. This stakeholder has a particular position in the process since she is the most direct beneficiary of the process. In fact, the entire rehabilitation process is based on the impairment or disability of the person and only exists because of the presence of this stakeholder (11, 12, 13). It is known that this perception has been challenged by ‘social model’ advocates, who state that disability or handicap arises from grave defects in society and social attitudes, and that these should be the primary targets for action (11, 14).

According to the manual, CBR programmes should be set up for “... the rural and urban poor, concentrating on the major categories of disabilities or handicaps caused by locomotor,

speech, hearing, seeing and mental disorders” (15). In practice, CBR projects are often set up for limited and selected groups of people with disabilities such as projects directed at specific groups of people with disabilities (e.g. people with mental retardation, people with locomotor disorders) or age groups (e.g. children, the elderly). Also, organisations can be identified, that offer a specific type of assistance or type of rehabilitation (e.g. medical, vocational, educational). Organisations have their own backgrounds and missions and are often part of, or related to, Ministries or Non-Governmental Organisations with a specific interest in certain aspects of disabilities.

Selection of the people with disabilities to be included in a CBR project is apparently done according to criteria set by other stakeholders and not by the people with disabilities themselves. Thus it does not necessarily reflect the needs of people with disabilities. However, research studies or reports that look specifically at the needs of the people with disabilities in CBR appear not to be available. In her article, Greenwood (16) pleaded for a needs-generated approach, but she does not include references of studies that have used this approach. It is therefore not known whether people with disabilities look for financial assistance, medical care, schooling, or vocational training and what the priorities for different groups of people with disabilities may be. Research within CBR projects is heavily biased, since people with disabilities will be tempted to ask for whatever they think the interviewer, as an extension of the service provider, has to offer. For example, if the interviewer is someone from social welfare they might ask for financial assistance, or if the interviewer is a medical person they might ask for medication or appliances.

The expressed needs of people with disabilities will depend on their perception of their position, their understanding of the disability, their ambitions, etc. Greenwood (16) wrote: “There is far too little research on group and individual meanings of disability”. And in an article on health problems in rural communities in Zimbabwe, Mutambirwa (17) stated that: “In many communities of the developing world formal health services are introduced without first understanding how the people perceive their health needs, health problems and what they do about them”.

Service providers (trainers, institutions) and people with disabilities differ in their opinions about the aims and methods of the rehabilitation process. This is painfully illustrated by

Kassah (18) when he describes a situation in Ghana where people with a disability did not want to participate in a CBR programme but would “rather migrate to the cities to beg”. There seems to be little research evaluating the differences between what service providers can offer and what consumers need. An exception is a study done by Van der Hulst (19) in which she discussed the difference in expectations between people with disabilities and rehabilitation workers involved in the CBR projects in Zimbabwe. She described it as a negotiation process in which both parties would try to realise their aims.

People with disabilities are, during the rehabilitation process, in direct contact with family trainers and volunteers, and indirectly, with rehabilitation workers at district, provincial, or national levels. People with disabilities have also formed organisations of their own (Disabled People Organisations, Independent Living Movements, advocacy movements etc.) to support each other and to express common needs. One of the founders of the National Council of Disabled People Zimbabwe (NCDPZ), Phiri, said: “what we had in mind had nothing to do with service; it was an advocacy or pressure group” (20). Service providers and disability movements both aim at improving the quality of life of people with disabilities, but they differ in their methods, means, and interests. These interests might be conflicting, but they can also be complementary to each other. Cornielje (21) reported a CBR project in Alexandra town where, after a difficult start, the disability movement now works together successfully with the Alexandra Health Centre. The disability movement is now represented in different local committees and takes part in the CBR courses.

One of the main reasons for introducing CBR in developing countries was the high numbers of people with disabilities whose needs have not been met by rehabilitation services. This number is commonly assessed through disability surveys and prevalence studies. Prevalence studies generally present the numbers of people with disabilities more than their needs or resources (22, 23, 24, 25, 26, 27, 28, 29, 30). It is surprising that so much attention is focused on prevalence studies. The outcome of these studies will invariably show high numbers of people with disabilities and will again confirm the limitations of the services available. In addition, it appears to be hardly possible to compare disability surveys and derive the needs of people with disabilities from such studies. The surveys do not only differ too much in terminology, but they also leave the basic question ‘what is a disability’, unanswered. This

might seem obvious when talking about someone who lost a leg through a land-mine accident, but what about someone with a mild learning disorder who is able to support her/his family, someone with dyslexia living in a rural area, or the woman who is not able to have children. Instead of merely establishing prevalence, research should aim at identifying the needs of people with disabilities and the resources through which people with disabilities manage their lives in families and local communities.

### **The Family and the family trainer**

The first caring environment experienced by a person with a disability is generally her own family. When including the family in the rehabilitation process, one has to first establish who is part of the family, what the expectations of the family are regarding the family member with a disability, and what type of support the family needs. According to research done by Singhi, Goyal, Pershad, et al. (31), families in India are affected by having a child with a disability. They observed that, “Families with disabled children perceived greater financial stress, frequent disruption of family routine and leisure, poor social interaction, and ill effects on the physical and mental health as compared to families of control children”.

Considering the importance attributed to the family, it is surprising that there is still little research about the involvement of the family in the rehabilitation process. O’Toole (3) commented that intervention programmes “... may become too highly child-focussed and overlook the wider needs of the family as a whole”. Not all parents welcome a teaching role and will find practising with their child with a disability rewarding. He concluded that parental involvement programmes could only be successful if these “... become an integral part of the mother’s day rather than making unrealistic extra demands on an already overburdened mother”. Mehretu and Mutambirwa (32) supported the statement that mothers are already overloaded with duties. They measured ‘time and energy costs of distance in rural life space of Zimbabwe’ and found that 25% of the daily time and energy budgets for each household member was spent on activities such as fetching water, collecting firewood, and grazing livestock. These activities are mostly carried out by women who also have the responsibility for the nutritional and health status of the other members of the household. They concluded that “...considering the role of wives (mothers) in rural settings in Africa, reduction of time

cost of distance and energy cost of distance associated with routine domestic chores may be given the highest priority”.

The main question appears to be whether or not the family is willing and able to train the family member with a disability. Families might have different, even unrealistic, expectations of rehabilitation. They might expect the rehabilitation workers to train and take care of the person with a disability, and they might not be aware that rehabilitation is often a long-term process and improvements sometimes come very slowly. Information on all aspects of the disabilities and on how people with disabilities can develop themselves, are essential for developing the motivation and realistic expectations of family members. In a research study about the CBR-projects in Zimbabwe, Finkenflügel et al. (33) observed a relation between the perceived ability to teach the child with a disability, functional skills and the expectations for the future of the child. Further research on the involvement of the families, i.e. how families can function as a caring and stimulating environment, is definitely needed.

#### **Community Rehabilitation Worker / Local Supervisor**

Community Rehabilitation Workers or Local Supervisors (later changed to ‘Local Facilitator’ (34)) do their work on a voluntary basis. Projects might make use of already existing cadres such as Village Health Workers or Community Workers and by asking them to devote part of their time to CBR alongside their other community activities. Some projects work with an ‘own’ group of volunteers and will sometimes provide incentives such as soap, food, or little presents, or they will give awards for the ‘volunteer of the year’ to express appreciation and provide motivation. Helander (35) explained that voluntarism is appreciated very differently in countries in Asia, South America, and West Africa. In some cultures, being a volunteer contributes to position and status, whereas in other cultures people are encouraged ‘not-to-work-for-nothing’. In some countries, community initiatives might even be perceived as subversive actions.

Not much is known about the motivation of volunteers in CBR. Are they involved because they want to do something with and for a community member with a disability? Are they looking for job opportunities or for some kind of financial gain? Another relevant question is whether or not we expect the community to support the Local Supervisor. Will the community compensate her for spending her time in the programme and thus giving up her ability to work on the fields?

Information on the position of the Local Supervisor is also scarce. Does she represent the community or the rehabilitation programme? In South Africa, the SACLA project worked with Community Rehabilitation Workers who were chosen by the 'community of handicapped people' (36). These rehabilitation workers were trained in an intensive four-week course and employed by SACLA. In CBR projects in Zimbabwe, it appeared not to be too difficult to find volunteers to do a house-to-house survey or work on a short-term assignment. It was more difficult and challenging to keep these volunteers involved and motivated in the follow-up stages of the projects (37).

Local Supervisors need training in order to be educated in the various aspects of the rehabilitation process. Training appears to be a good reinforcement for keeping volunteers involved. Training can be organised using the WHO-manual (15, 38) but always needs to be tailored specifically to the situations that the volunteers will come across during their work. No studies are carried out regarding the impact of training, i.e. regarding how and to what extent the interventions of the Local Supervisors will be changed as a result of the knowledge and skills gained in the training.

#### **Stakeholders at the district, provincial, and national level**

The stakeholders described in this paragraph are people involved at the district, provincial, and national level. Again, it is possible to identify many more (latent) stakeholders. At these levels, people generally function within organisations and thus answer to the goals of an organisation as well as their own private goals. Organisations have to achieve 'public' goals but there are discrepancies between goals like, "health for all by the year 2000" or, "integration of people with disabilities" and the 'own' goals of an organisation or leading persons in those organisations. In her article with the controversial title, "Reorienting health care in Africa - can the élite believe in equity?", Einterz (39) illustrated this by saying that the "...reorientation of funds requires those in power to slash and scatter their power base". The question then is: 'Do we really expect people in influential positions to give up privileges or redesign a system that will make them replaceable, superfluous or less important?' Organisations might also adopt aims and objectives that have not yet been accepted by the other stakeholders in the rehabilitation process or are not seen as a priority. One example is the policy on gender issues in health; some organisations make it an explicit objective to make health care available

to women. Some organisations involved in rehabilitation choose only to assist co-operatives for women, or to pay school fees for girls with disabilities only. This preferential policy is difficult to explain to communities, community leaders, and rehabilitation workers. It simply comes down to the fact that organisations have their own specific aims. Organisations of professionals will primarily look at the interests of the professionals they represent, and project or donor organisations will have a desire to survive and thus will choose projects that strengthens themselves. Choices might also be fuelled by a desire to get good publicity and to be attractive for employees, donors, etc. There is always a chance that these types of aims may become a more important issue, than providing services that will be beneficial to people with disabilities. Therefore, organisations should be approached as an entity with its own goals. In addition, one should be on the alert if an organisation's goals aim towards empowerment of people with disabilities and strive for a high level of involvement in decision making for all "stakeholders" in the rehabilitation process. Often, these organisations get nervous when people with disabilities want a real say in the organisation itself and want to influence goal setting, distribution of resources, and staff employment. The main stakeholders within the professional rehabilitation services will be discussed hereafter.

### **Rehabilitation Assistant / Intermediate Level Supervisor**

The Rehabilitation Assistant or Intermediate Level Supervisor is, in most programmes, a formally trained professional. She could be a nurse, a social worker, or a teacher with a few months additional training, or she could be a rehabilitation worker with a one to two year training in rehabilitation and different professional backgrounds (e.g. in medical rehabilitation, vocational rehabilitation, special education, or social work). In practice, it will be the aims and objectives of the programme, rather than the needs of people with disabilities, that determine what type of education is required for this position.

In Zimbabwe the Ministry of Health started a "Rehabilitation Technicians Training School". Initially the Rehabilitation Technicians (formerly called: Rehabilitation Assistants) were seen as an affordable way to provide rehabilitation for people with disabilities. It was presented as a short-term solution because, in the long run, it was foreseen that enough physiotherapists and occupational therapists could be trained to attend to people with disabilities in the future. However, these rehabilitation technicians have acquired a specific role in, and are now an

essential part of, the practice of decentralisation of rehabilitation services in Zimbabwe (40, 41, 42). McLaren (43) proposed a four-tiered rehabilitation delivery system for rural health services in KwaZulu, South Africa. At the rural level, paraprofessional workers (rehabilitation therapists) recruited from their own area of work under supervision of professional therapists. Dolan, Concha, and Nyathi (44) conducted a study also in South Africa, on the training of Community Rehabilitation Workers who, after a two-year training, became entirely community-based and only used the district hospital as a referral centre and resource base. These Community Rehabilitation Workers worked directly with people with disabilities and thus appear to have combined the Local Supervisor and Intermediate Level Supervisor into one person. Cornielje and Ferrinho (45) and Deetlefs (46) described the training and practical experiences of Community Rehabilitation Facilitators. During this two-year training programme, rehabilitation was approached as part of community development. Training focused on the enhancement of knowledge and skills in community development, and thus contrasted with medically-oriented training. In Malawi, Malawi Against Polio (MAP) trained MAP-assistants for their outreach rehabilitation services (47). Overall, there are a lot of differences in the type of training (duration, contents, and teaching methods), and in the positions occupied by these rehabilitation workers. They might be perceived as 'assistants' of the established rehabilitation professionals, or they might be seen as responsible persons who are supervised but work independently with Local Supervisors and people with disabilities.

### **Trainer**

According to the WHO-CBR model, trainers are professionals in referral centres at district/provincial levels working in the fields of education, health, or vocational training. These professionals train and supervise Intermediate Level Supervisors and additionally will provide diagnostic and rehabilitation services for people with disabilities referred to them by Intermediate Level Supervisors. These professionals (nurses, physiotherapists, occupational therapists, social workers, teachers, vocational trainers) usually run CBR projects. Some projects have even been run by the people with disabilities themselves (the most famous example is probably project Projimo) (48, 49, 50) but in these cases they are not likely to use the term CBR for their projects. In practice, 'community' participation in management of CBR projects is minimal and is usually in the hands of (non-disabled) professionals.

Mendis, a physiotherapist by training and involved in CBR from the start, comments on the role of the physiotherapist in primary health care in developing countries. She argues that there is a "... need to reconceptualise our role in rehabilitation along the lines of the new approaches so that we are capable of guiding primary health workers, the community, the family and the disabled in the total rehabilitation process" (51). McAllister (52), an Irish physiotherapist, wrote about her personal experience in Zimbabwe. She appeared to be impressed by what is, and can be achieved, although she pointed out that expatriate therapists encounter many frustrations and limitations in their work, as it involves many administrative duties. Therapists who become trainers in CBR projects are often forced to change roles. Occupational therapists and physiotherapists are trained to assess the limitations in function of the person with a disability, to set treatment objectives, and to provide direct, hands-on therapy, often with the use of equipment. In CBR, trainers only work indirectly with people with disabilities. Their task is to train the intermediate professionals and to organise training and feedback sessions for them. Trainers should be able to transform often complex treatment practices into functional skills that Intermediate Level Supervisors can understand, use, and pass to Local Supervisors or, depending on the type of CBR project, the family trainer. In the WHO-manual (38), and also later by O'Toole (53), this has been called the 'de-mystification' of rehabilitation. Although many of the skills to be learned by Intermediate Level Supervisors and Local Supervisors may be new, it is also important to realise that people have always dealt with people with disabilities and have some understanding of (ab)normal development, the problems that people with disabilities encounter, and the ways in which people have solved problems so far. A well-documented example is the way mothers in Jamaica handle their children. They traditionally use a set of handling routines to test and train their children and adapt these routines if the child is not responding in the expected manner (54, 55, 56). This example shows that already existing knowledge and skills can be used as a basis for learning new or additional skills. Elaborating on Mendis' quote stated earlier, it can be said that trainers build on existing knowledge, break down complex practice to functional skills, have a good understanding of how, when, and where the skills are being used, use different training methods, and organise feed-back and follow-up sessions. To conclude, it is important to point out that it is not only medically trained professionals that get involved in CBR. For example, the School of Social Work in Zimbabwe offered a one-year Certificate Course in Rehabilitation (57).

### **Specialists**

'Specialists' include highly qualified professional rehabilitation workers and medical doctors in training institutes and treatment centres at the national level. Like the therapists at the provincial level, they are available for people with complex disabilities and the stakeholders working directly and indirectly with them. The distance between specialists and the community and living space of the person with a disability is large. Therefore, the amount of time spent by a specialist on an intervention (advice, prescription of drugs, operation, intensive training etc.) will be limited. Aftercare, (re-) socialising, etc. will be left to trainers and Intermediate Level Supervisors, Local Supervisors, and family. As such, the role of specialists in CBR is limited.

### **Anticipating the influence of stakeholders**

Having identified, and discussed the different stakeholders involved in CBR, the next step in this stakeholders analysis is to anticipate the influence these stakeholders will have in the CBR process. The word 'influence' refers to the 'position' in the process, the 'competence', and the 'decision making capability' of the stakeholder. These aspects underlie the concept of 'empowerment', which was defined before as, "to give the power to act". The 'position' of each stakeholder in the process has already been described extensively. 'Competence' will be used here to describe the level of authority, ability, skill, knowledge, and attitude of the different stakeholders.

The influence of a stakeholder is best seen in the decision-making processes. The main question here, is to what extent the different stakeholders will be able to adapt or change their role in the process. Are the stakeholders (i.e. the Local Supervisors and Intermediate Level Supervisors) perceived as 'extended arms' of the trainers and thus merely play an instrumental role in CBR? Or do all stakeholders operate more or less autonomously within their area of competence and make all necessary decisions? Are they able to change objectives, target groups, training contents, etc. by themselves?

First, the anticipated competency level of the stakeholders will be discussed, followed by a discussion of their 'decision making capability'. This will provide a framework to be able to assess the efficacy of stakeholders in CBR. As such, it also functions as a

normative framework. This framework will also benefit the development of strategies to obtain effective support for CBR (defined as step 3 in the stakeholders analysis).

### Competency levels of stakeholders

An overview of the different stakeholders involved in CBR has been constructed on the basis of different editions of the manual (15, 38, 58), adjoining documentation (51, 59, 60) and articles focussing on specific groups of stakeholders (40, 44, 61). This information is summarised in table 1. The table can be used as a normative framework to compare actual positions and competencies with the theoretical ones presented in the table which might reveal the need for additional training, support, etc. However, the table cannot be used as a blueprint for involving stakeholders in a specific project. In fact, each CBR project will have to define the competencies of stakeholders on the basis of the specific, and sometimes unique, objectives of the project and the local circumstances. For example, in some Muslim communities, women might be restricted from visiting the homes of others, and therefore would not be able to fulfil the roles of Local Supervisor and Intermediate Level Supervisor in the same way as, for example, women in Jamaica or Zimbabwe who are used to being out of the home for household duties, farming, etc. and can thus visit other homes easily.

**Table 1. Competency-levels, decision-making capabilities and information needs of the stakeholders**

	<b>Competency</b>	<b>Decision-making (examples)</b>	<b>Information needs</b>
Person with a disability	<ul style="list-style-type: none"><li>- Assess own situation, expectations, ambitions and perspectives of her/his own life and goal setting for the rehabilitation process</li><li>- Select a trainer</li><li>- Negotiate with trainer on goals to be reached and assistance required</li></ul>	<ul style="list-style-type: none"><li>- Perceived her own role in different settings-</li><li>Choose training (type, frequency, efforts), the use of aids and appliances, and who can assist to realise ambitions</li></ul>	<ul style="list-style-type: none"><li>- The potential to fulfil her own perceived roles as a family member, a pupil, a businessman etc.</li><li>- The effectiveness of training</li><li>- The usability and availability of aids and appliances</li><li>- The existence of support and advocacy groups</li></ul>

<p>Family /Family trainer</p>	<ul style="list-style-type: none"> <li>- Support the person with a disability,</li> <li>- Analyse the situation, and set goals (i.e. with children or with people with a mental handicap or illness)</li> <li>- Train the person with a disability</li> </ul>	<ul style="list-style-type: none"> <li>- Perceive role of the person with a disability and the type, frequency and duration of training in case the person with a disability cannot speak for her/himself</li> <li>- Determine contents, methods and intensity of training</li> </ul>	<ul style="list-style-type: none"> <li>- The current abilities of the person with a disability in relation to the desired abilities and individual capacity (incl. the use of aids and appliances)</li> <li>- Specificity (right type of training), effectiveness (are expected results reached) and efficiency (number of people with disabilities trained related to time spent with them) of training methods</li> </ul>
<p>Community rehabilitation worker (CRW) / Local Supervisor (LS)</p>	<ul style="list-style-type: none"> <li>- Perform (functional) assessment of the person with a disability covering ADL and relate this to the goals set by person with a disability and draw up a plan for training</li> <li>- Train the person with a disability and instruct the family member(s)</li> <li>- Identify obstacles in the community that prevent the person with a disability from reaching her goals and/ or to participate in community activities</li> <li>- Mobilise community (awareness, acceptance, accessibility, attitudes etc.)</li> </ul>	<ul style="list-style-type: none"> <li>- Determine number of family trainers trained</li> <li>- Determine methods used to train families / family trainers</li> <li>- Determine contents, frequency and duration of training</li> <li>- Suggest community members and organisations to be involved</li> </ul>	<ul style="list-style-type: none"> <li>- The current abilities of the (referred) person with a disability in relation to desired abilities and capacities</li> <li>- Number of people with disabilities trained by the family (trainer), effectiveness and efficiency of training</li> <li>- Effectiveness of training and perceived competence of family (trainer)</li> <li>- Involvement of community in training and changes in physical and social structures to make these accessible for people with disabilities</li> </ul>
<p>Intermediate local supervisor (ILS)</p>	<ul style="list-style-type: none"> <li>- Train CRWs/LSs- Assess, treat and instruct people with disabilities referred to a rural or district health centre</li> <li>- Support community rehabilitation workers in mobilising communities</li> <li>- Oversee daily running of rehabilitation programme in the district (operational)</li> </ul>	<ul style="list-style-type: none"> <li>- Determine number of CRWs trained</li> <li>- Determine contents, frequency and duration of training of CRWs</li> <li>- Provide support for CRWs regarding training family trainers and involving community members</li> <li>- Determine use and distribution of resources</li> </ul>	<ul style="list-style-type: none"> <li>- Effectiveness of training of CRWs, number of CRWs involved, workload of CRWs, perceived competence of CRWs</li> <li>- The abilities of the (referred) person with a disability in relation to the desired abilities and capacity</li> <li>- Effectiveness of the CRWs</li> </ul>

			<p>in mobilising communities</p> <ul style="list-style-type: none"> <li>- The availability of resources (manpower and funds) in relation to the objectives of the programme and its efficiency and effectiveness</li> </ul>
Trainer	<ul style="list-style-type: none"> <li>- Train LSs/RAs</li> <li>- Assess, treat and instruct people with disabilities referred to a provincial, national or specialised health centre.</li> <li>- Initiate and facilitate rehabilitation projects in the districts (tactical)</li> </ul>	<ul style="list-style-type: none"> <li>- Determine number of ILSs trained</li> <li>- Determine contents, frequency and duration of training of ILSs</li> <li>- Provide support for ILSs in training CRWs</li> <li>- Determine use and distribution of resources for existing and new programmes</li> </ul>	<ul style="list-style-type: none"> <li>- Effectiveness of training of ILSs, number of ILSs involved, workload of ILSs, perceived competence of ILSs</li> <li>- The abilities of the (referred) person with a disability in relation to the desired abilities and capacity</li> <li>- The availability of resources (manpower and funds) in relation to the initiation of a rehabilitation programme, the objectives of the programme and its efficiency and effectiveness</li> </ul>
Specialist Project planners, implementers	<ul style="list-style-type: none"> <li>- Provide professional education of therapists-</li> <li>- Assess, treat and instruct people with disabilities referred to a specialised centre</li> <li>- Take overall responsibility for rehabilitation projects, including organising support for the project and manpower planning.</li> </ul>	<ul style="list-style-type: none"> <li>- Determine number of trainers trained</li> <li>- Determine contents, frequency and duration of training of trainers</li> <li>- Provide support for trainers in training ILSs</li> <li>- Acquisition and distribution of resources</li> </ul>	<ul style="list-style-type: none"> <li>- Effectiveness of training of trainers, number of trainers involved, workload of trainers, perceived competence of trainers</li> <li>- The abilities of the (referred) person with a disability in relation to the desired abilities and capacities</li> <li>- The availability of resources in relation to the mission statement, the number of people with disabilities, the expectations of the people with disabilities, and the objectives reached at the different levels</li> <li>- The efficiency and effectiveness of the rehabilitation programme in relation to other initiatives working with a similar mission statement and objectives</li> </ul>

### **Decision-making capability of stakeholders**

Descriptions of the competency levels of the stakeholders should be combined with an analysis of the 'decision-making capability' of these stakeholders in CBR. In projects where the stakeholders function as 'extended arms', a management model with a strong 'chain of commands' will be found, whereas a model based on a 'chain of support' will be suitable in situations where the stakeholders operate autonomously. These two models can also be referred to as, 'top-down' and 'bottom-up' approaches, respectively. Also, countries will differ in their socio-economic circumstances, cultural backgrounds, political systems, etc. and these differences will be reflected in their decision-making processes. CBR is, like other development programmes, presented as a bottom-up approach (35) with a strong involvement of people at the community level. If, and how, this approach conflicts with traditional and modern politics in some countries, is not documented in the literature about CBR. Discussing decision-making in CBR also implies discussing the ownership of the project and thus probes the issue of empowerment of the different stakeholders. It can be concluded from what has been said before, that CBR projects are very often owned by organisations (government, NGO) and that 'collective' programmes like Project Projimo are still exceptions to the rule. The 'owners' of CBR projects usually include 'empowerment' as one of the objectives of the project. However, this objective addresses only one group of stakeholders: the people with disabilities.

A few comments regarding the availability of information to stakeholders in CBR should be made in this section. Stakeholders need information upon which they can base their decisions to adapt or change the intervention or the process. Information collected by the different stakeholders for monitoring and evaluation purposes, often serve the programme owners only. To value and increase the decision-making capability of the stakeholders, it is necessary to include information that is useful for the stakeholders themselves, for the stakeholders they support, and for the stakeholders they have to account to. Examples of decision-making by the different stakeholders, and their related information needs, are provided in table 1.

### **DISCUSSION**

This review of the different stakeholders involved in CBR illustrates that the rehabilitation process can be described as a complex system of interactions between stakeholders and within groups of stakeholders. Research on the competency levels and influence of each

stakeholder is still in its early stages and the available documentation is fragmented. In order to set up effective programmes and to assess how and why CBR-projects do (or do not) work in the expected way, different stakeholders should be approached as the main focus of, and participants, in the study. This requires a theoretical cadre in which the prospected competence and efficacy of the different stakeholders are directly related to the objectives of the project and in which the interventions by the stakeholders have been made explicit.

A stakeholder analysis, as used in this chapter, is a promising method to explore and analyse the working processes in CBR. It not only provides insight into the roles of the different people involved and makes these accessible for assessment and research, but it also reveals opportunities to improve the process. There is, however, a risk of 'constructing reality'. CBR projects might be more diffuse than can one would assume based on the literature and the stakeholder analysis in this paper (e.g. in situations where people involved in CBR have different and inconsistent roles, the project lacks a clear structure, the competence level of the stakeholders do not match the decision-making capabilities, or the information flow is non-existent or only serves a specific group of stakeholders). It is also important to realise that the diversity within a group of stakeholders can be vast. This has already been discussed in the context of people with disabilities and the community, but it will definitely apply to the other stakeholders as well.

A group of stakeholders that have not been discussed are the local authorities who have their power base in the community. They often have to share this power with traditional leaders or political parties. Thus, stressing and developing the competence of different stakeholders in combination with empowering people with disabilities and their families, can easily be seen as a challenge to existing power structures.

A group of stakeholders in CBR includes a wide diversity of people with a wide range of interests. Some groups have organised themselves in support or pressure groups, e.g. Disabled People Organisations, parents organisations, and alliances of professionals. These different groups will advocate their interests in policy making, division of funds, etc.

Although CBR has initially been presented as a humanitarian programme (and thus suggests that disability and rehabilitation are not political issues), it is important to realise that stakeholders have their own interests in the project. This personal interest might fully serve the project

(for example a rehabilitation technician who wants to increase her competence and enters additional training), but it might also detract from the projects' objectives.

Regarding the information needs of the different stakeholders, it is stressed here that information collection should be consistent with, and supportive of, the decision-making capabilities of the stakeholders. Monitoring and evaluation instruments generally calculate the number of people involved in the project, the number of appliances given, the number of children with disabilities going to a mainstream school, etc. Some instruments collect an impressive amount of data (62, 63), but it is not clear if and how the different stakeholders can actually use the data to assess and improve their own effectiveness and that of the stakeholders they support.

In concluding this analysis, the role of stakeholders in CBR has not been explicitly linked to the specific objectives of CBR projects. So far, the roles of stakeholders have been derived from a general concept and understanding of CBR. With regards to the reservations encountered in the division of CBR as a concept, similar reservations exist in the discussion of the role of stakeholders in the rehabilitation process. In order to overcome these reservations, it is important to link the project objectives directly to the perceived roles of the stakeholders involved.

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